

**NHS BLOOD AND TRANSPLANT  
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**

**BOWEL ADVISORY GROUP MEETING**

**Working Party on Geographical equity of Access to  
Intestinal Transplantation in the UK  
Teleconference - 25<sup>th</sup> September 2014**

Attendees: Dr Steve Middleton (Chair)  
Dr Elisa Allen  
Prof Peter Friend  
Dr Girish Gupte  
Dr Jonathan Hind  
Prof Elizabeth Murphy  
Dr Trevor Smith (BAPEN)  
Mrs Kamann Huang (Secretary)

Apologies: Prof Darius Mirza

**ACTION**

**Aim of meeting**

To discuss whether there is likely to be geographical inequity of access to intestinal transplantation in the UK and develop strategies to resolve any current inequity and monitor this in the future.

**1 Is there equity of access in the UK to intestinal transplantation?**

S Middleton raised this question and the group agreed that due to the small numbers of patients who have received intestinal transplant in the UK it would not be possible to draw firm conclusions about geographical equity of access to intestinal transplantation from this cohort. There was therefore agreement that analysis of equity of access to intestinal failure management and parenteral nutrition would be a useful guide. If access to intestinal failure management was not geographically equitable then it could be assumed that access to intestinal transplantation would also be non-equitous.

T Smith reported that according to the British artificial nutrition survey (BANS) there is a wide geographical variation in the rate of new and established home parenteral nutrition in the UK. The 2013 report indicated a prevalence of 4 patients per million on home parenteral nutrition (HPN) in the North compared to 13 per million in the south-east. This has been interpreted as indicating inequity of access to HPN on a geographical basis. Therefore the group felt this data could reasonably be extrapolated as an indication that there was currently inequity of

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access as the majority of patients undergoing intestinal transplantation are referred from intestinal failure centres for complications of HPN.

P Friend enquired about the progress of the regionalisation of intestinal failure care through the Home Intestinal Failure Network (HIFNET) process as this seemed critical to gaining equity of access to home parenteral nutrition and intestinal failure management.

T Smith commented that there had been considerable delays in the HIFNET process and the best case scenario would be to formally designate regional centres in April 2016. There were originally plans for around 10 centres but after evaluation of 32 potential centres in the UK it is more likely that there will be around 20 centres designated. There have been issues with the momentum of this process and leadership has now been moved to the colorectal CRG and it is hoped that this will speed the process up. There have been considerable delays in receiving reports after assessment of centres and some of this data is felt to be out of date. As a result it may be necessary to collect more recent data from certain centres which again will cause a delay in designation.

P Friend asked if there were hard guidelines regarding the designation of centres.

T Smith indicated that there had been greater clarity generated regarding this issue. For instance centres should deal with more than 20 patients per year with type III intestinal failure and have more than five patients who have been receiving home parenteral nutrition for more than five years with a catheter related sepsis rate of less than 5/ 1000 days of outpatient parenteral nutrition.

S Middleton asked if the HIFNET process could be supported by BAG in any way to facilitate its progress. There was agreement amongst the group that a letter of concern about the lack of progress in formal designation of regional intestinal failure centres should be sent by the national Bowel Advisory Group (BAG) to the appropriate offices (these will be indicated by T Smith in a further correspondence). This letter should be managed through the Bowel Advisory Group and should appear as an agenda item at the next meeting and sent by D Mirza, the Chair of the group.

D Mirza

**2 Should the rate of referral of patients to intestinal transplantation centres from the regional intestinal failure centres be monitored as a further measure to confirm equity of access?**

S Middleton raised the second question for debate regarding monitoring of referral rates of intestinal failure centres to transplant centres.

P Friend agreed that there was a hierarchy of steps to equity of access, the initial one being equity to intestinal failure management and

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subsequent to this, referral from intestinal failure managing centres to intestinal transplant centres. Therefore it would be logical to audit this referral rate which could be compared across centres and normalised as required for different types of patients.

Agreed points to take forward:

G Gupte asked who would be responsible for undertaking the audits. There was general discussion about the role of the British artificial nutrition survey (BANS) and T Smith informed the group that the survey was recently revised and now gathers far more detail about patients. This would help in acquiring appropriate data and it may be possible in the future to include data on referral of patients to intestinal failure centres.

P Friend suggested that an audit of deaths of patients with intestinal failure receiving parenteral nutrition would be a useful indicator of appropriate referral patterns.

J Hind suggested that referral criteria should be clear so that these can be used as indicators for audit compliance.

G Gupte mentioned that these criteria have already been developed by the Bowel Advisory Group working party and these documents are available.

S Middleton suggested that the criteria for referral to an intestinal failure centre should be reviewed to ensure that they remain appropriate and useful for the purposes of this audit before they are circulated to regional IF centres (following the designation of the centres as part of the HIFNET process).

These notes will be presented at BAG at its next meeting and further activity of the working group directed by BAG.

**Dr Steve Middleton**  
**25<sup>th</sup> September 2014**